

Pandemic Is a Tragedy, And a Chance to Rethink Long-Term Care

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he COVID-19 pandemic has been a tragedy for hundreds of thousands of older adults in the U.S. and their families. It has amplified and exposed the nation's already deeply flawed system of long-term supports and services (LTSS). Yet it also has created a historic opportunity to rethink our model for caring for frail older adults and younger people with disabilities.

The COVID-19 crisis did not spring from nowhere. Indeed, while many close observers of the nation's long-term care system have been shocked at the amount of illness and death among older adults, they were not entirely surprised.

The pandemic focused attention on questions that often have been ignored by policy makers and even by providers. Does the nation's long-term care system provide care in the setting that is most appropriate for each frail elder? Does it provide the right person-centered care? Does it effectively integrate supports and services with medical treatment? Are there enough direct care workers and are they properly trained? Has the nation dedicated sufficient resources to finance the care older adults deserve?

The answer to each of those questions is "no." And COVID-19 has exposed the consequences. The way we care for older adults in the U.S. is, self-evidently, not working. The Kaiser Family Foundation estimates that as of Oct. 8, 2020, there were least 537,000 COVID-19 cases and 84,000 deaths in long-term care facilities. At least another 83,000 older adults living in the community have died from the disease, according to the Centers for Disease Control and Prevention.

The indirect effects of COVID-19 are severe as

well. Millions of older adults have been isolated from family and friends for months. While data are limited, families and operators of care facilities report that residents are prematurely dying from the effects of social isolation.³

How can we prevent this from happening again?

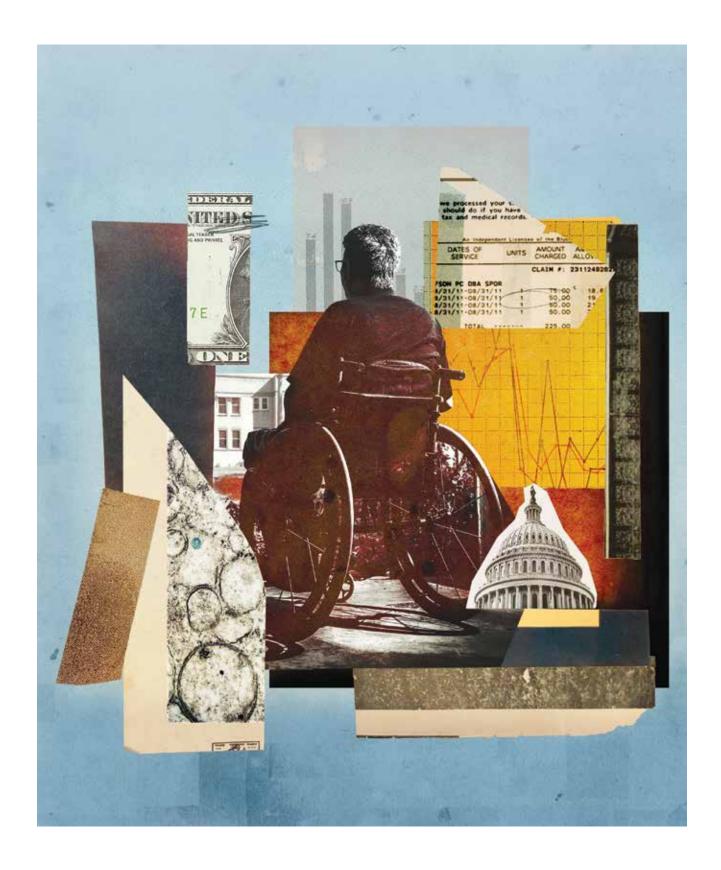
Start with where frail older adults live.

Today, 85% to 90% of those with long-term care needs — or about 12 million people — receive care at home. Many get this assistance with the support of family members and some have the help of paid aides.

But that care often is built on a flimsy foundation. Spouses and adult children often provide care with great love — and little skill. Few communities have programs to teach family caregivers the skills they need, for example, to safely transfer a frail spouse from a bed to a chair. Many family caregivers have no idea where to ask for help with transportation. Meal delivery services such as Meals on Wheels are underfunded and suffer from long waiting lists.⁴

Without that solid infrastructure, those aging at home are likely to suffer from social isolation or require emergency department visits or hospitalizations. For example, many older adults who visit

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emergency departments are found to be suffering from malnutrition.⁵

Another 700,000 older adults with physical or cognitive limitations live in assisted living or other residential care, and nearly all pay out-of-pocket. Under limited circumstances, Medicaid will pay for services, but not room and board, in these settings. Thus, assisted living is available for those with the financial resources — at a cost averaging \$4,000 per month.⁶ And they often are

not set up to provide the high level of personal assistance that many older frail adults require.

Finally, about 700,000 people live out their days in nursing homes.⁷ Roughly 80% of those long-stay residents receive Medicaid.⁸ While they may need a high level of personal assistance, few need skilled nursing care. Thus, the vast majority have no clinical

reason to live in such a facility. They are there largely because Medicaid creates powerful incentives for them to do so, even if other settings are more appropriate. This arises from four interrelated circumstances.

- Medicaid pays for room and board in nursing homes, but nowhere else a strong incentive for recipients to choose a nursing home over settings where they would have to pay their own rent. This model also means operators overvalue real estate relative to the services they provide.
- Medicaid eligibility varies by state, but financial requirements often are less rigorous for a nursing home resident than for someone receiving care in the community.
- Nearly all states finance their share of Medicaid in part by imposing provider taxes on nursing homes. Those taxes generally are based on patient revenue. Thus, states have an incentive to steer Medicaid beneficiaries to nursing facilities because they generate significant revenues.
- Medicaid home and community-based services (HCBS) are available in each state, but often are severely underfunded. That means long waiting lists or benefits that are insufficient to provide quality care for those living at home.¹⁰

But because Medicaid payments are so low, nursing homes have built up a second business post-acute care — that is funded much more generously by Medicare. The result: A model of care where (pre-COVID-19) frail older adults who are highly vulnerable to infection often shared buildings, dining rooms, day rooms, and even bedrooms with people just discharged from hospitals, where infection is common.

The pandemic also further exposed the gaps in the direct care workforce. About 1,000 long-term care facility staff have died from COVID-19.¹¹ It appears that coronavirus often was brought in by staff, who either were asymptomatic or who

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came to work despite symptoms. Many were poorly trained in infection control. Many may have spread the disease by working in multiple settings. Direct care workers often work two or more jobs to make up for low wages.

Yet, the risks of viral infections in long-term care facilities were well-known before the pandemic. Every year, nursing homes suffer outbreaks of seasonal flu or the intestinal norovirus.¹²

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On the revenue side, the pandemic accelerated the shift of lucrative post-acute care to home or other less costly congregant settings. This change has been driven in part by changing consumer preferences. But it also comes from the managed care plans that now insure one-third of Medicare beneficiaries and are looking to place members in less costly post-acute care settings. And those that still send members to nursing facilities pay an average of about 20% less than traditional Medicare.

At the same time, state Medicaid budgets are under severe pressure because of COVID-19, and nursing home reimbursement rates are likely to remain frozen or even decline. Facilities may also lose revenue if, for post-COVID-19 regulatory or

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market reasons, they will have to eliminate semiprivate and even quad rooms.

At the same time, facilities are seeing significant cost increases, including for personal protective equipment and coronavirus testing. Even before the pandemic, labor rates were rising due to a growing shortage of aides, nurses and other staff. COVID-19 has driven compensation even higher, at least temporarily.

Facilities face significant capital costs as well. Many are more than 40 years old and need to be remodeled. And the effects of the pandemic may require significant redesign to reduce the spread of infectious disease among residents and staff.

Not everyone with cognitive and physical limitations can stay in their own home, especially if they have no family members to care for and advocate for them. But they could live in less costly, less medical settings than a nursing home.

For many older adults, small group homes and similar alternatives could be more appropriate. But they are inaccessible for many families who cannot afford to pay out-of-pocket. And state laws that limit the services aides can provide make creative staffing difficult. For example, in many jurisdictions, nursing assistants cannot administer routine over-the-counter medications unless they are directly supervised by a nurse.

The flaws of the current payment system affect more than care settings. They also create perverse incentives for care delivery by building a financial and regulatory wall between medical treatment and personal assistance for those with chronic illness. Medicare pays for health care but generally not long-term care. For those eligible, Medicaid pays for long-term care but not health care.

This creates two problems.

First, this model discourages states from enhancing their Med-

icaid long-term supports and services. To the degree that better LTSS could reduce emergency department visits and hospital stays, it could save significant money. But today those cost savings flow to the federal Medicare program, not to the states that expand their LTSS programs.

Most important, this bifurcated payment model acts as an impediment to families who need fully integrated health care and personal assistance. They currently must navigate two enormously complex and disconnected systems.

For example, physician offices rarely inform patients about sources of personal care. Hospital discharge planners have neither the time nor the knowledge to prepare a patient or her family for her care needs when she returns home. This is another reason why many families default to postacute care in a nursing home.

In this enormously challenging environment, what could a new model look like?

Frail older adults and younger people with disabilities, with support from family and a case manager, would choose the care setting and supports that would help them live the best life possible. It could be a group home, traditional assisted living, a nursing home or their own home. But the decision would be based on what is most clinically and socially appropriate, not on the constraints of an outmoded payment system.

The vast majority of those receiving longterm care at home are getting their support from unskilled relatives. Health systems, insurance companies or government could make caregiver training a benefit. Perhaps family caregivers could even be paid.

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Whether they are working in facilities or in people's homes, they are paid less than a living wage for what, even before COVID-19, was an extremely dangerous job.¹⁴ Long-term care providers will create a quality workforce only by paying competitive wages and benefits.

Those with chronic disease and physical or cognitive limitations should have services wellcoordinated and tailored to their individual needs, not driven by an outdated and dysfunctional payment system.

Long-term supports and services would be well integrated with medical treatment, with no regulatory or payment barriers, and through a financial model that creates incentives for strong chronic care management. This could be delivered through managed care plans, such as Medicare Advantage (MA) or fully integrated models such as the Program for All-Inclusive Care for the Elderly (PACE). They also could be provided through expanded special needs plans (SNPs), which are MA plans targeted to members with specific needs. For example, Institutional SNPs

serve those who live in the community but who would need institutional care without the additional services offered by the plan, such as care coordination, or nutrition or transportation.

Delivering fully integrated care through traditional fee-for-service Medicare would be more challenging but still possible. The many value-based models now being tested could create incentives for primary care practices to partner

with, for example, community-based organizations to deliver fully integrated medical and social care. It might also be possible in traditional Medicare through Medicare Supplement (Medigap) insurance.

A public program such as Medicaid would continue to support long-term care for those with very low incomes. But Medicaid would be far more flexible than today, and the default setting for care would be people's own homes, not nursing facilities. Medicaid HCBS programs would be more generously funded, and long waiting lists could be eliminated.

States should better align Medicaid LTSS with other public services, such as low-income housing, transportation, home delivered meals, adult day services and primary medical care. For example, the asymmetry of using Medicaid funds to pay for room and board in a nursing home and nowhere else could be addressed by shifting all government housing support to a separate program. This could free up Medicaid dollars to pay for services and supports.

Similarly, Medicaid and state housing programs could work together to build out a model

of housing with services, where low-income residents of subsidized housing could receive some basic supports as well as routine nursing care.

Medicaid also needs to be flexible enough to provide non-traditional services. For example, the CAPABLE program, designed at Johns Hopkins University School of Nursing, combines social supports, occupational therapy and modest home repairs, all aimed at helping older adults remain at home. The program lowers costs and improves participants' quality of life. 15

State and local governments provide many of these services today, but in a disconnected way. Like specialist physicians, each program cares

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for just part of a person, not her whole life. The agencies that deliver these programs need to work with one another to provide flexible, holistic care. California is one state working to design such a model.

While Medicaid would continue to assist those with low incomes, everyone else would pay for their long-term services and supports through a mix of private savings (including home equity) and self-funded, universal public insurance. It could be operated through Medicare or as a separate government program.

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Where will the additional funding for all this come from? The reality is that few Americans have saved sufficiently for the cost of long-term care in old age, few have private long-term care insurance, and Medicaid does not have the resources to support this care for the fast-growing Baby Boom generation.

A public long-term care insurance pro-

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gram could supplement out-of-pocket spending, especially for those with true catastrophic costs that few private long-term care insurance policies cover. A cash benefit (with care management) would let older adults decide where to live and give them the flexibility to purchase the services they need. Such a program could supplement managed LTSS benefits delivered through a health plan.

Washington state already has adopted a modest public long-term care insurance plan. A half-dozen other states, including California, Minnesota and Illinois, are exploring similar ideas. And there is some interest in Congress.

Such a program would not only benefit older adults, but it also could save substantial Medicaid dollars. Over the long run, the Urban Institute estimated a mandatory public catastrophic LTC benefit could reduce Medicaid LTSS spending by as much as one-third. ¹⁶

Long-term care in the U.S. was failing long before COVID-19. But now that this terrible disease has exposed its flaws, we have an opportunity to fix them. We may not get to an ideal model, but many intermediate solutions already are on the table. With the political will, we can vastly improve a failed system that is needlessly killing our seniors before their time.

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NOTES

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